

J A N U A R Y 8 - M A R C H 1 9 , 2 0 0 0

Hospice: A Photographic Inquiry

PRESENTED

LOCALLY BY

HOSPICE FOR

THE CAROLINAS



Nan Goldin

Amalia, Amanda and Jennifer

New York City, 1994

ilfochrome print



Sally Mann
Untitled (from Windows), 1992
gelatin silver print

Hospice: A Photographic Inquiry

Organized by the Corcoran Gallery of Art and the National Hospice Foundation, *Hospice: A Photographic Inquiry* explores the collaborative experience of hospice care through the eyes of artists. The Corcoran Gallery of Art commissioned five internationally recognized photographers – Jim Goldberg, Nan Goldin, Sally Mann, Jack Radcliffe, and Kathy Vargas – to create new works about hospice for this exhibition. Also included is a film by Susan Froemke, Deborah Dickson, and Albert Maysles, produced by Home Box Office for national broadcast.

Why an exhibition?

In some ways, the underlying principles of hospice and photography are similar. Both hospice workers and the artists included in this exhibition have engaged in intimate, philosophical exchanges with other people. Both are on journeys of self-discovery. Both reveal new and deeper insights about life to other people. For this project, each artist worked closely with caregivers, patients, and families. They reveal in their work the feelings and vision gained from their experiences. The resulting exhibition emerged from such trusting, long-term relationships.

The work of contemporary artists often mirrors the social realities of the times. Artists can elucidate issues that are psychologically complex, clarifying the work of scientists, sociologists, journalists, and politicians. During the past hundred and thirty-five years, photographers have produced pictorial essays about social conditions, drawing attention to such topics as the human cost of war, the urban landscape, immigrant poverty, child labor, politics, and environmental concerns. *Hospice: A Photographic Inquiry* was created by the Corcoran Gallery of Art and the National Hospice Foundation to reflect this tradition. It includes new works by a number of creative artists in order to explore and communicate to the public the experience and meaning of hospice care.



The Light Factory

L I F E S H A R I N G

Hospice: *A legacy of*



Jim Goldberg

August 17, 1993 (detail)

dye diffusion transfer (Polaroid) print

Hospice for the Carolinas is the two-state association representing 100 hospice providers in North and South Carolina. The organization provides support to local hospice programs in both states through technical assistance, educational services, and advocacy in the state legislatures, state regulatory bodies, and Congress. Hospice for the Carolinas was formed in 1993 with the merger of Hospice of North Carolina, established in 1977, and Hospice of South Carolina, established in 1979. Hospice care is currently available in every North and South Carolina county. In 1998, more than 16,000 patients were served in North Carolina and more than 7,000 in South Carolina.

For more information or assistance in locating a hospice in your area, please call 1-800-662-8859.

Q. What is hospice?

A. Hospice is a concept of health care that provides holistic services for the physical, emotional, and spiritual needs of terminally ill patients and their families. Today, individuals and policy makers are confronted with difficult choices about health care, particularly at the end of life. Questions of cost, availability, quality, and patient autonomy are debated by families, health care providers, and politicians. For an increasing number of patients and families, hospice is an enlightened development in the history of medicine. The goal of hospice is not to cure illness or hasten death, but to ease a patient's passage from life. A philosophy of care

rather than a place, the hospice concept has gathered broad acceptance in the United States during the past twenty years. Hospice helps patients and their families to decide the course of their health care with assistance from their doctors and hospice professionals. Hospice care is designed to alleviate pain and control the symptoms of disease with expertise and compassion. In addition to physical care, hospice provides spiritual, social, and emotional support.

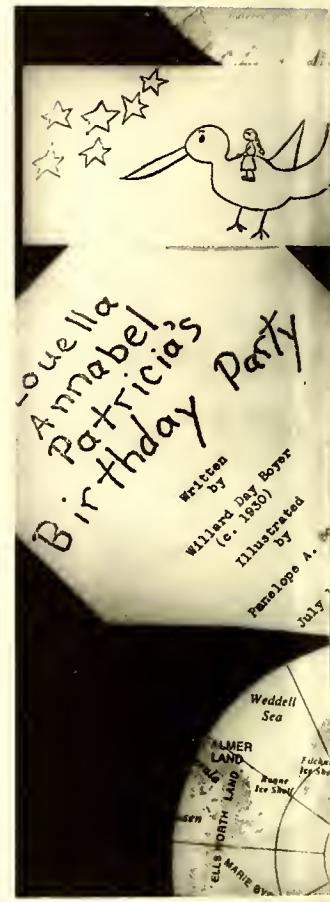
Hospice patients typically have a prognosis of six months or less to live.

Q. Does hospice only take care of cancer patients?

A. No. Although cancer patients represent a majority of their patients, hospice continues to serve those who are at the end-stage (having a life expectancy of six months or less) of any disease. Indeed, as health care changes and chronic diseases increase, hospice serves a wide range of patients. Other diagnoses commonly seen in hospice include diseases of the heart and lungs, AIDS, ALS (Lou Gehrig's disease) and Alzheimer's.

Q. What is the history of hospice?

A. Hospices were not always devoted solely to the care of the dying. In fact the word "hospice" (derived from the same root as "hospitality") can be traced to Roman times. In medieval Europe, it referred to way-stations where weary travelers could rest, pregnant women could give birth, and the ill could recover or find a peaceful death. The modern hospice movement was begun by Dr. Cicely Saunders in London in 1967. Patients were provided with the best medication possible to control their pain so they and their families could address both the emotional and spiritual challenges they faced. Saunders wrote



Kath
Papa Day (detail) 1995 mixed media

that the process of dying "is the search for who you are, what the world is about, and what your place in it somehow is"

Q. What impact has hospice had in the United States?

A. In 1968, Florence Wald, then dean of the nursing school at Yale, brought the idea of hospice to the United States. Now hospices across the

United States care for nearly twenty percent of all dying patients. This increasing acceptance of hospice care is, in part, a reaction to the great advances in medical care made during the past fifty years. Doctors are trained to seek cures for diseases, even when there is little hope for recovery. Rather than attempt to keep a patient alive at all costs, hospice offers a humane alternative to aggressive medical treatment for the terminally ill. "While hope for a miracle cure may not be evident in hospice philosophy," states Jay Mahoney, former president of the National Hospice Foundation, "hospice care can be an extraordinary expression of hope and individual courage." This philosophy of hope is at the heart of the hospice movement, which is made

up of local, statewide, and national networks of care providers. In the United States, these networks include over 2,800 hospices that cared for more than 540,000 patients in 1998. Hospice care is now a covered benefit under most public and private health plans, including Medicare. In fact, a 1995 study shows that for every dollar spent on hospice by Medicare, \$1.52 was saved in government Medicare expenditures.



Hand-colored gelatin silver prints

Q. How does hospice work?

A. According to a 1996 Gallup poll, nine out of ten of those surveyed said that, if given six months to live, they would choose to be cared for and die in their own homes, or in those of family members. Once a patient selects hospice care, an interdisciplinary team of doctors, nurses, nursing assistants, social workers, counselors, therapists, spiritual caregivers, and volunteers is assembled. A comprehensive plan is developed by the patient, family, and hospice team which supports the hospice patient's decision to remain at home. Hospice care also is available in many nursing and rest homes and assisted living facilities. Each hospice patient usually has a "primary caregiver." This caregiver is most often the patient's spouse, partner, or parent, although any family member or friend can fulfill this role. Members of a hospice team visit the patient and family regularly to provide medical and social services and to support the caregiver. Some hospices also have available acute care in-patient facilities where patients with acute medical needs are cared for by hospice-trained staff and volunteers. Today, hospice employs more than 25,000 paid professionals and approximately 96,000 volunteers contribute more than five million hours of services.

Q. When is it time to refer a patient to hospice and who does it? For example, should I wait for our physician to refer us to hospice or should I raise the issue first?

A. Any time during a life-limiting illness, it is appropriate to discuss all of a patient's care options, including hospice. By law, the decision belongs to the patient. Understandably, most people are uncomfortable with the idea of stopping an all-out effort to "beat" the disease. The hospice team is highly sensitive to these concerns and is always available to discuss them with the patient, family, and physicians. Since some physicians may feel uncomfortable bringing up hospice care, a patient or caregiver should feel free to bring up the topic. A patient, friend, family member, or pastor may make a hospice referral. People with life-limiting illnesses may have months versus years to live; early referral enables the hospice team to develop the relationship needed to more fully meet the needs of the patient and caregivers. If the patient continues

to meet hospice criteria, services may continue past six months.

Q. What does the hospice admission process involve?

A. One of the first things hospice will do is contact the patient's physician to make sure he or she agrees that hospice care is appropriate for the patient at this time. The hospice care goals and available services will be reviewed carefully with the patient and caregivers to make sure they understand them. The patient will be asked to sign consent and insurance forms similar to those signed when entering a hospital.

Q. Does hospice do anything to make death come sooner?

A. Hospice does nothing to hasten or unduly prolong the dying process. Hospice provides a presence and specialized knowledge during this particularly difficult time. Hospice services are designed to bring comfort, to control pain and other symptoms, and to address the emotional, social, and spiritual needs of both the patient and his/her loved ones.

Q. How difficult is it to care for a loved one at home?

A. While it is never easy, some caregivers have said it was an especially rewarding period of their lives, a time when they could express love and caring in a personal and meaningful way. One of the first things hospice will do is work with the patient and caregivers to prepare an individualized care plan. The hospice team works closely with the patient and caregivers to address these needs. The hospice team visits regularly and is always accessible to answer questions and provide support. Residents of the Carolinas are fortunate in that there is a strong network of hospice providers who have focused their services on the varying needs of the communities they serve. Hospice teams include medical directors, nurses, social workers, counselors, chaplains, nursing assistants and volunteers. These teams help coordinate medications, supplies, equipment, hospital services, and additional helpers in the home, as appropriate. While friends and family give most of the care, hospices do have volunteers to assist with errands and to provide an occasional break.

Q. Is the home the only place hospice care can be delivered?

A. No. Although most hospice services are delivered in a private residence, some patients live in nursing homes, assisted living facilities, or hospice centers.

Q. How does hospice manage pain?

A. Hospice has expertise in managing pain. Not only are hospice staff up-to-date on the latest medications and approaches for pain and symptom relief, but they also recognize and understand that emotional and spiritual pain are just as real. The hospice team is uniquely skilled at addressing the needs of patients and their caregivers during this difficult period. With hospice care, many patients can be as alert and comfortable as they desire.

Q. How is hospice care funded?

A. Hospice coverage is widely available. It can be provided through Medicare and Medicaid in both North and South Carolina as well as by most private insurance plans. If coverage is not available, hospice will assist in investigating other resources the family may not be aware of. Barring this, most hospices provide care by using money raised in the community from memorials, special events, foundation gifts, or other contributions.

Q. Hospice says it provides bereavement care to the family. What does that mean?

A. Bereavement care refers to the organized program of grief support provided by a hospice to caregivers and families. Based on the needs of the caregivers, a plan of care is developed following the patient's death. This might include individual counseling, support groups, or informational mailings. Family members also can call to request additional support any time during the year following the death of their loved one. In addition, many hospices sponsor bereavement functions and support groups for the community.



Who are the artists?

JIM GOLDBERG

A pioneer in socially relevant photography, Jim Goldberg establishes sustained contact with his subjects, shedding light on entire cultures and social attitudes through his juxtapositions of pictures and words. He is perhaps best known for his book *Rich and Poor* and for *Raised by Wolves*, a recent book and exhibition about runaway teens in San Francisco and Hollywood. Goldberg collaborated with his own family for *Hospice: A Photographic Inquiry*. He photographed his father who died in hospice care at home in Florida. "I was able to be with my parents during my father's death and experience hospice firsthand," says Goldberg. "Hospice was our safety net. They were the given, the trust. Hospice became an integral part of our lives; it was the antithesis of how the medical profession works. . . . The bottom line is that it's important to be there for our families, whether it's with a camera or without one."

NAN GOLDIN

Nan Goldin's brightly colored photographs often reveal the intimate details of intense interpersonal relationships. As an innovator in sequencing images to tell complex stories with few words, she uncovers contemporary attitudes, stereotypes, fears, and emotions about sexuality, gender, illness, and social roles. Goldin's past work includes her books *The Ballad of Sexual Dependency* and *The Other Side*. Her photographs for *Hospice: A Photographic Inquiry* reveal both the spirit and vulnerability of AIDS patients in New York City and Long Island. "I needed to face my own denial of death and learn more about how people come to accept mortality," says Goldin. "I wanted to document – as much as possible – the complexity of the people I photographed and the interiors of the spaces they lived in. It was fascinating to see the differences in each person's acceptance of death and the roles that human love, spiritual belief, and humor play in this process. I realized that the only thing that separates me from the dying is time."

SALLY MANN

Sally Mann's work is at once documentary and mythic. It combines a pictorially romantic, visually seductive style with a penetrating view of human nature. Mann's own family is the ongoing subject of her work; she has explored adolescence and family intimacy in books such as *At Twelve: Portraits of Young Women* and *Immediate Family*. After interviewing hospice patients in Lexington, Virginia, Mann created a new series of metaphoric images that are often coupled with writing. This series of photographs depicts the dreams, desires, and memories of the terminally ill patients she met. "I hoped to discover something universal about how we approach death," says Mann. "I was in search of what exactly it is that matters to the dying person and how hospice tries to provide those things. This question – of ultimate desire – has interested me for a long time. In the same way that my children ask, 'What would you take out of the house if it were on fire?' I wondered whether the trivial or transcendent assumes greater importance in our final months. I suspected it might be the former, just as my own answer to the fire question is never 'my art' but always 'the scrapbooks.'"

JACK RADCLIFFE

Jack Radcliffe's photographs rely on his long-term immersion in particular themes that interest him. Best known for his penetrating portraits, Radcliffe has previously documented the urban poor and middle-class teens. His subjects reveal themselves with uncanny directness and clarity. Radcliffe spent three years photographing patients, family members, and caregivers in an AIDS hospice in York, Pennsylvania. "At York House I photographed over and over in the same three rooms. I wanted to show hospice patients as people with names, personalities, and identities," he says. "I wanted to reveal the relationship of my subjects to their environment. Soon I had to find new visual solutions to this problem. I changed my perspective and moved in closer to the patients. This realization, in turn, has transformed my photography."

KATHY VARGAS

Kathy Vargas is a photographer, curator, and director of the visual arts program at the Guadalupe Cultural Center in San Antonio, Texas. She creates composite hand-colored photographs that are sometimes shown together with objects in installations. For this exhibition, Vargas interviewed hospice caregivers, patients, and their families in San Antonio, Houston, and Austin. By combining pictures and text about these people with symbols of their mortality – their X-rays, medical charts, personal possessions, and mementos – she documents both the joy and grief of the hospice experience. According to Vargas, “Photography is a mediation between that moment we can control, when an image is made, and those beyond our control, in which the image will continue without us . . . But the essence of the life of the beloved always dwells in the memories of those who continue to love and remember. I wanted to show that persistence of love and memory, along with the role hospice plays in encouraging it.”

MAYSLES FILMS, INC.

Susan Froemke, Deborah Dickson, and Albert Maysles of Maysles Films, Inc. were commissioned by Home Box Office to create a film about the hospice experience for national broadcast at the time of the opening of *Hospice: A Photographic Inquiry*. Also on view in the exhibition, their film entitled *Letting Go: A Hospice Journey* combines the stories of three hospice patients: an eight-year-old boy in Missoula, Montana; a 46-year-old cancer patient in Queens, New York; and a 62-year-old man in Santa Rosa, California.

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Hospice: A Photographic Inquiry was organized by the Corcoran Gallery of Art, Washington, D.C., in collaboration with the National Hospice Foundation. Major funding has been provided by Warner-Lambert, a pharmaceutical and consumer products company, as part of its ongoing commitment to supporting hospice care in the United States and around the world. The exhibition has also been made possible by a generous gift from The Project on Death in America, funded by the Open Society Institute, a non-profit foundation that supports the development of open societies worldwide. Additional support has been received from the National Endowment for the Arts, The Prudential Foundation, the Glen Eagles Foundation, and Learning Design Associates, Inc.

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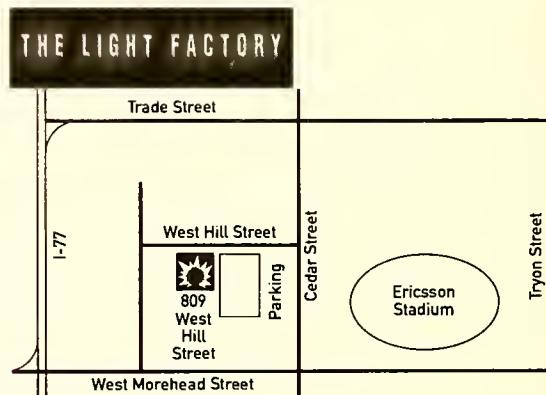
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Street address: 809 West Hill Street in the warehouse district of Third Ward. Exhibition hours: Wednesday & Friday 10am - 6pm, Thursday 10am - 8pm. Saturday & Sunday noon - 6pm and 24 hours a day on the Web (www.lightfactory.org). Free admission.